

# Ensuring Timely Access to Care for People With HIV Infection: A Public Health Imperative

The continuing importance to public health of the HIV epidemic is reflected in the number of HIV-related articles published in the Journal. Our focus on HIV this month reflects the editors' ongoing desire to publish new research and commentary on the key challenges associated with addressing HIV as a public health problem. As the range of articles in this issue suggests, there are few if any areas of public health that have not been affected by the HIV epidemic.

Just over 20 years into the epidemic, we have learned much about HIV, how it is transmitted, who is potentially at risk, and how HIV infection might be treated. This progress has been made even as our knowledge base has shifted and expanded. We have learned to define (if not always adopt) sound public health strategies and policies based on the science as we know it. And we have not been afraid to adapt our approaches as our scientific knowledge evolves—for example, attitudes toward early HIV testing and early HIV treatment have changed as our understanding of behavioral and treatment interventions has changed.

That said, hubris would be inappropriate. As we begin the third decade of the epidemic, we still have far to go. In some respects, as much as we have learned about HIV, we have not succeeded on some very basic fronts—most important, in the core public health functions of ensuring that people learn their HIV status, reduce their risky behaviors, and have access to new treatments that might prolong life.

## THE PROBLEM OF LATE DIAGNOSIS

At a recent conference, data from the US Centers for Disease Control and Prevention (CDC)

were released showing that in 25 states with HIV reporting, 41% of people infected with HIV learned their status long after infection, either at the same time as or within 1 year of an AIDS diagnosis.<sup>1</sup> A CDC 12-state study of persons with AIDS found that overall, 40% either had AIDS at the time of their HIV diagnosis (18%) or developed AIDS within 1 year of their first positive HIV test (22%). Overall, 45% of those participating in this survey indicated that illness was the primary reason for their having an HIV test.<sup>2</sup>

These dismal findings are evidence not only that people infected with HIV are in some way disconnected from the health care delivery system, as indeed many are, but also that those who are in the system are not getting properly screened or are not getting access to needed care. For example, among persons reported with HIV/AIDS for whom payer status was known, 22% were receiving Medicaid at the time of their diagnosis—that is, they were in a care system, one that will pay for HIV testing. Even so, 48% of those diagnosed with HIV and receiving Medicaid were diagnosed with AIDS within 1 year after being tested for HIV. Those with private insurance fared worse: 52% of their diagnoses were late.<sup>3</sup>

These studies suggest that even when individuals present to the health care system with conditions that suggest high risk for HIV infection, they are not necessarily being offered testing in a systematic way. A 1997 study at one public hospital found that 62% of inpatients with newly diagnosed AIDS had previously received inpatient or outpatient medical care from that hospital, with a mean of 4 encounters over the previous 12 months, frequently for conditions that should have signaled a need

for HIV testing before the test was ultimately given.<sup>4</sup> The good news is that subsequent interventions at that hospital increased outpatient HIV testing.<sup>5</sup>

## THE IMPORTANCE OF BEING TESTED

It should be noted that some people make a conscious decision not to seek testing. In the CDC's HIV Testing Survey of individuals at high risk for HIV infection, it was found that the main reasons for avoiding or delaying testing were fear of learning one is HIV-positive, thinking one was unlikely to have been exposed to HIV, thinking one was HIV-negative, not wanting to think about the possibility of being HIV-positive, and thinking there is little that can be done about being HIV-positive.<sup>6</sup> These data suggest the importance of identifying ways to overcome these attitudes to promote earlier testing.

Evidence exists that knowledge of one's serostatus, in addition to being the first step toward receiving appropriate treatment, also promotes prevention-oriented behavior. In a CDC study of 180 persons with recently acquired HIV infection, 90% reported adopting some change in sexual behavior after learning their HIV serostatus, including 60% who used condoms more often and 49% who said they had sex less often. Another very important finding from this small survey was that those who were receiving health care for HIV infection were more likely to report changing their sexual behavior (93%) than were those not receiving care (81%).<sup>7</sup>

These data and many of the HIV-related articles in this issue suggest several research and policy questions that the public

health community must address in the third decade of the epidemic.

## KEY RESEARCH AND POLICY QUESTIONS

*How do we make HIV risk assessment, HIV testing, and HIV prevention an integral part of the health care delivery system?* Most testing occurs in the context of the health care delivery system, yet it occurs late in disease progression. In part, the discussion surrounding the CDC's Serostatus Approach to Fighting the HIV Epidemic (SAFE) initiative<sup>8</sup> attempts to address this problem. But we must also pay special attention to the integration of prevention services in those financing or delivery systems (e.g., Medicaid and Medicaid managed care) where a high proportion of those infected with HIV are ultimately identified and receive care. We must also begin to address the implications of our treatment advances and their impact on the adoption or maintenance of risk reduction behaviors, as reflected in Katz et al.<sup>9</sup>

*How do we address HIV-related stigma, which affects both the competence of providers to address HIV risk behaviors, prevention services, and treatment and the willingness of those with HIV or at risk for HIV infection to seek out these services?* Herek et al.<sup>10</sup> and Valdiserri<sup>11</sup> both suggest that homophobia, among other factors, remains a major impediment to successful prevention interventions. External homophobia creates fear of seeking out services and may make those services culturally inappropriate. (This is also true for other "phobias" associated with HIV, including attitudes toward substance users and toward heterosexuals who are sexually active outside marriage.) But the internalized homophobia Valdiserri references,

which can mediate risky behavior on the part of men who have sex with men, may well be more detrimental to the prevention effort.

This is an area where only limited research has been undertaken. How does public health take on the issue of homophobia, not just to alter the behavior of society in general by destigmatizing homosexuality, but to undertake interventions at the community level among gay, lesbian, bisexual, and transgendered persons that will be effective in helping them overcome the internalization of this stigmatization?

The overwhelming response to the Journal's June 2001 issue on lesbian, gay, bisexual, and transgender health demonstrates the demand for good data on this issue. The level of research needed can be achieved only with an investment of resources from the federal government through the National Institutes of Health and the CDC. We now have overwhelming data to support the need for such research for public health, not political, reasons. It is time for those agencies to act forcefully on this issue as a public health problem.

*How do we hold the health care delivery system accountable for better adherence to identification strategies for those at risk for HIV infection and consistent adherence to care regimens?* Arno's brief on using an index of *Pneumocystis carinii* pneumonia to measure performance of health systems is one step in that direction.<sup>12</sup> But much more needs to be done toward public health's having the lead in defining the appropriate standard of care for the health care delivery system.

The job starts within the Department of Health and Human Services, which recently chose to remove from a proposed regulation of Medicaid managed care plans a requirement that these plans follow

the department's own HIV antiretroviral treatment guidelines.<sup>13</sup> With that requirement removed, Medicaid beneficiaries will have no guarantee of consistency of treatment across Medicaid managed care plans—a challenge for the individual patient but also an issue of great public health importance, because inconsistent treatment approaches may promote the development of a drug-resistant virus. It is important to remember in this context that Medicaid officials estimate that more than half of people living with HIV/AIDS in the United States have their care financed by Medicaid.<sup>14</sup>

It is our hope that future issues of the Journal can be a forum for discussion of research and commentary on these issues. ■

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